Compassionate Allowance Outreach Hearing on Brain Injuries

Social Security Administration

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Statement of

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Mr. Commissioner, thank you for the opportunity to describe our work involving service members with traumatic brain injury (TBI). I would first like to comment briefly on what is known about prognosis in TBI, and then present some of the findings from our published reports.

## TBI Prognosis

Our ability to predict which patients with acute traumatic brain injury (TBI) will have severe disabilities years later is limited. Patients with even devastating injuries regularly show substantial improvement over time. However, from a population perspective certain variables at initial presentation reliably indicate a poor prognosis.<sup>1,2</sup> These variables include older age, poor level of functioning prior to injury, and substance abuse. Additional factors relevant in the acute and sub-acute phases of care are hypotension, intracranial hemorrhage, skull fracture, duration of coma, duration of post-traumatic (anterograde) amnesia, and low Glasgow Coma Scale<sup>3</sup> (GCS) score. Predictive models incorporating multiple variables have been developed, but these models are not readily applicable for use in individual cases. To be useful in predicting long-term recovery for individuals, specific cutoffs would have to be derived from data not available in published reports.

<sup>&</sup>lt;sup>1</sup> Silver JM, McAllister TW, Yudofsky SC., Eds. Textbook of Traumatic Brain Injury. Washington, DC: American Psychiatric Publishing, 2005, pp 16-20.

<sup>&</sup>lt;sup>2</sup> Willemse-van Son AHP, Ribbers GM, Verhagen AP, Stam HJ. Prognostic factors of long-term functioning and productivity after brain injury: a systematic review of prospective cohort studies. Clin Rehab. 2007;21:1024-37.

<sup>&</sup>lt;sup>3</sup> The GCS evaluates the basic neurologic functions of eye-opening, motor capacity, and verbal response.

In practice, rehabilitation experts have used a wide range of measurement tools to assess how patients progress over time, and to tailor rehabilitation services. Some of these tools have been widely used for several decades. Because these tools are typically applied as patients are making the transition from acute care to rehabilitative care, usually some weeks after the traumatic event, these assessments may be useful predictors of long-term disability. Among the most consistently applied measures is the FIM,<sup>™</sup> a proprietary tool.<sup>4</sup> The FIM<sup>™</sup> consists of 18 items, some pertaining to motor function (eating, grooming, bathing, dressing, toileting, transfers, and locomotion) and some relevant to cognitive function (comprehension, expression, social interaction, problem solving, and memory). Each of the 18 items is rated on a 1–7 scale, so that total scores range from 18–126. A score of 18 indicates the lowest level of independence. In VA rehabilitation units, polytrauma patients, including those with TBI, are categorized on admission and at discharge based on the FIM.<sup>™</sup>

## Inspector General Reports

We evaluated the medical care provided for a group of service members who had suffered TBI during or after service in Afghanistan or Iraq. All of these individuals had been treated in military treatment facilities and then transferred to one of VA's four polytrauma rehabilitation centers. Those centers are in Tampa, FL, Richmond, VA, Minneapolis, MN, and Palo Alto, CA. Injured service members typically receive approximately one month of inpatient treatment during the initial period of their rehabilitation. While there, VA specialists measure the functional capacity of each individual when they are admitted and just prior to discharge.

The Office of Inspector General, Department of Veterans, identified a group of patients who had completed initial inpatient rehabilitation in 2004. Our healthcare inspectors, most of whom are registered nurses, completed comprehensive inperson assessments with 52 of these patients 1-2 years after discharge to assess their functional status and continuing need for supportive services. Interviews were conducted in 23 states and the District of Columbia.<sup>5</sup> Two years after those interviews, we tried to contact all of those 52 individuals again, and were able to obtain follow-up information on all but one.<sup>6</sup> We are therefore able to comment on the status of this group of injured services members at three points in time over a 3-4 year period after injury.

As expected, most of the 52 patients were young adult men (median age, 24.5; range, 19-48; female, 3). Somewhat more surprising, however, was that most of the injuries occurred <u>after</u> these service members had returned from combat zones (36, 69%), and most of these TBI cases resulted from motor vehicle

<sup>&</sup>lt;sup>4</sup> Originally referred to as the Functional Independence Measure, the FIM<sup>™</sup> is a product of the Uniform Data System for Medical Rehabilitation, Amherst, NY.

<sup>&</sup>lt;sup>5</sup> The full report is available at <u>http://www.va.gov/oig/54/reports/VAOIG-05-01818-165.pdf</u>.

<sup>&</sup>lt;sup>6</sup> The follow-up report is available at <u>http://www.va.gov/oig/54/reports/VAOIG-08-01023-119.pdf</u>.

accidents (30/36, 83%). To a large degree, therefore, the experience of these service members reflects that of many unfortunate young people throughout American society.

Based on examinations made by VA rehabilitation specialists at the time of admission, these 52 patients had been categorized according to the extent of their functional independence. When we examined them in follow-up 1-2 years later, we used the same measurement instruments in order to estimate their progress. Almost all of these patients showed some improvement over time.

For the purposes of these hearings, I would like to focus on the eight persons who showed the least functional independence at the time they began VA rehabilitation approximately eight weeks after injury. These individuals required assistance with all the aspects of motor function that are measured – eating, grooming, bathing, dressing, toileting, transfers, and locomotion. When we visited them in follow-up, all were substantially improved. However, none was fully independent and two remained institutionalized.

Earlier this year – now more than 3 years after their initial TBI rehabilitation at a VA hospital – we interviewed 41 of the 52 original patients or their families. Of the 11 patients who were not interviewed, 10 had evidence of recent VA health care or were on active duty. Focusing again on those eight who started out with the most severe disabilities, one remains institutionalized and five continue to require major support at home. One veteran was living with his family on an Indian reservation and attending school; although he reported that he was attending school full-time, he also described having been fired from several jobs because he was "too slow." Only one patient, a man who was attending school full-time and planning to become a teacher, was living independently. See Figure.



Clinical Course of 8 Severely injured Service Members with TBI, all of whom began rehabilitation in the lowest functional group

Although I am highlighting the experience of eight service members considered to have the worst injuries, many of the other patients suffered catastrophic losses in their abilities to think, work, and carry on with their lives. Only 17 of the 41 veterans we interviewed this year were working or attending school full-time. Many of these patients present tremendous challenges to healthcare providers and families.

For example, a 29-year-old soldier suffered a TBI when a large tire exploded after his return from Iraq. At our initial visit, his wife described times when he was up all night punching the wall and pacing the floor. She said he had once assaulted his 12-year-old child and all his children kept away from him. They had plans to move to another state where they both have extended families. When our team returned in early 2008, he was divorced and frequently staying in shelters. He had visited VA hospitals in three different areas, but often missed appointments and failed to take prescribed medication.

The toll on families has been particularly tragic. We learned of wives and mothers forced to quit their jobs to take care of their injured loved ones, and of children sent to distant states to live with relatives while a wife provided care for her husband.

We did not collect information on receipt of Social Security benefits, but information about sources of healthcare and VA disability payments are instructive. Twenty-two of 41 patients reported receiving non-VA health care, mostly by TRICARE,<sup>7</sup> and eleven indicated multiple sources of healthcare funding.

By early 2008, 40 of the 52 patients were receiving monthly compensation payments for service-connected disabilities. See Table below. Twenty-five patients had 100 percent service-connected disability ratings, and 8 of these had been found to be impaired enough to require "aid and attendance" or "housebound" support. Five patients were awarded compensation benefits prior to discharge from inpatient rehabilitation. For the remaining 37 patients, the median time from discharge after inpatient rehabilitation to an initial decision to award compensation benefits was 53 weeks (range 10–132). Two patients with 10–20 percent ratings received no payments while collecting military severance pay.

Service- Connected Rating (percent)	Number	Annual Compensation median (range)
0	10	\$0
10–20	4	\$702 (\$0–1,404)
30–50	4	\$7,440 (\$4,272–10,200)
60–90	9	\$17,280 (\$11,052–32,028)
100	25	\$35,952 (\$30,324-88,788)

VA compensation received by 52 TBI patients as of December 2007. For one patient, data pertain to February 2008.

## **Conclusion**

The long-term outcome for patients with TBI can be difficult to predict, but patients and families clearly need extensive support in the early weeks and months of recovery. Numerous readily available clinical data could be employed to gauge reliably expected short- and long-term employability. The timing of measurement, use of demographic and clinical variables, and cut-off points for outcome predictions need to be specified. Fortunately, large data bases currently exist and much of the work has already been done. The time is right to establish ways for providing much-needed support early on, with recognition that support for families is critical to the recovery of patients and well-being of their children.

Thank you once again for the opportunity to address this panel about the challenges faced by patients with TBI, and their families. I will attempt to address any questions you might have.

<sup>&</sup>lt;sup>7</sup> TRICARE is the Department of Defense's health care program for members of the uniformed services, their families and survivors, as well as retired service members.